

Illinois Department of Children and Family Services
Institutional Review Board Meeting
Minutes
November 27, 2018

CHICAGO

Janet Ahern
Janet Chandler
Dr. Margaret Scotellaro
Brooke Taylor

ON PHONE

Robin Albritton
Tammy Fuller
Arricka Newingham

CALL TO ORDER

Janet Ahern called the meeting to order at 2:02 p.m. A quorum was present.

APPROVAL OF MINUTES

MOTION: Tammy Fuller made a motion to approve the minutes September 25, 2018.

Robin Albritton seconded the motion, Arricka Newingham, Margaret Scotellaro and Janet Chandler abstained, and a unanimous vote from the remaining board members carried the motion.

MOTION: Margaret Scotellaro made a motion to approve the minutes October 23, 2018.

Janet Chandler seconded the motion, Robin Albritton, Tammy Fuller and Arricka Newingham abstained, and a unanimous vote from the remaining board members carried the motion

FOLLOW UP

LaShonda Tate. *How the Social Determinants of Health Influence Contraceptive Decision Making of Young Mothers who are Youth in Care*

Researcher completely redid submission. Much better.

No concerns. All previous concerns that were raised were changed.

MOTION: Tammy Fuller motioned to approve the proposal.

Robin Albritton seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

NEW PROPOSALS

Dr. William Ferguson. *PEDS-PLAN: Pediatric Precision Laboratory Advanced Neuroblastoma Therapy.*

Experimental procedure. Completed four cycles now.

Using standard treatment and adding on. Rare that intervention has worse outcome than the standard.

Looking at genetic traits of tumor. Looking at targeted treatment based on genetic traits of the tumor.

Tested and matched with a research medication (FDA approved) for adults, but not for children/youth.

Oral drug given daily.

Tolerating the medication well. No control group. Everyone assigned a drug based on their tumor.

Second drug DMFO (experimental) has good results in children with neuroblastoma – unsure if the youth will be getting that. One getting DMFO, one getting standard treatment. Once you get to maintenance therapy, everyone gets it whether getting earlier is better.

Not in best interest to stop treatment. Need two other doctors opinions (St. Louis doctors).

Experimental requires the consent of the parent as well.

Researcher would like to retain tissue samples, blood samples, bone marrow and tumor tissue samples.

Good medical procedure for children.

MOTION: Margaret Scotellaro motioned to approve the proposal.

Robin Albritton seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

Neil Jordan. *How Family Strengths Affect Outcomes of Foster Youth Across Development.*

Analysis of existing data they already have. Statistical analysis of existing data.

No consent/assent concerns.

Outcomes should be good. Should get the outcome desired.

Just measured by the CANS.

MOTION: Margaret Scotellaro motioned to approve the proposal.

Janet Chandler seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

James Tonsgard. *A Phase II Study of Cabozantinib (XL 184) for Plexiform Neurofibromas in Subjects with Neurofibromatosis Type I in Children and Adults.*

Youth has elephant man disease. Tumor the size of golf balls and rapidly growing and he has scoliosis.

Immune modulator medications.

This one is the best option, has been studied in others and has been quite successful. Shrinkage at 20% and is up to 40-50%. Most studies are done in adults.

Drug could do good – decrease pain.

Mostly tolerated and regulated/monitored well.

MOTION: Margaret Scotellaro motioned to approve the proposal.

Rocell Cyrus seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

OTHER

Introduction of new board member Rocell Cyrus.

Discussion around Chapin Hall information.

Pamela Lilisten from New Jersey Family Services contacted Janet Ahern on information about the IRB in Illinois is run.

Next meeting was scheduled for December 18, 2018 at a 2 PM.

The meeting adjourned at 3:02 p.m.